NHS to LHS: How can big data transform the National Health Service into a learning health system?

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Conflicts of interest

- 30% clinical, 70% academic
- Advisory boards: Novo Nordisk, Boehringer-Ingelheim, Pfizer, Astra-Zeneca
- Research funding: Innovative Medicines Initiative, European Research Council, NIHR, HEFC, British Heart Foundation, BMA Research Foundation
- Trustee, South Asian Health Foundation
- Research interests: digital health, EBM, informatics, medical education

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THE MESS

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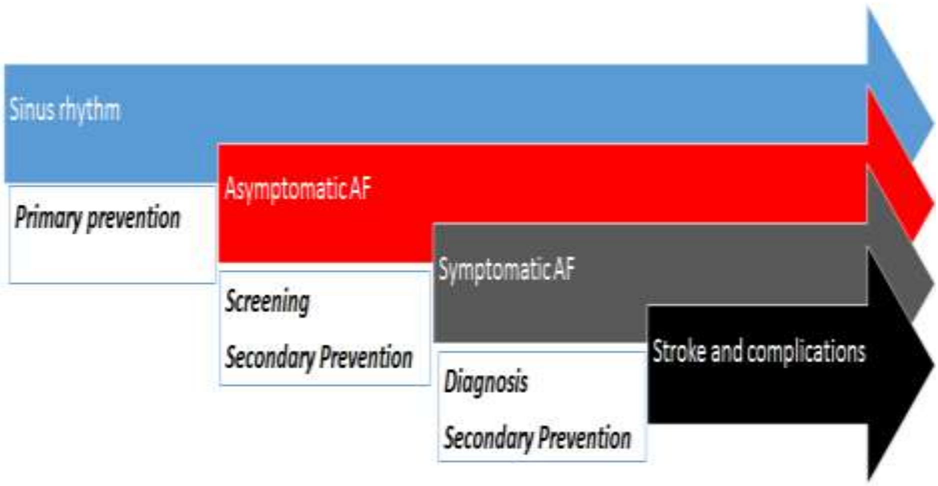
Save our NHS

At the bedside

- 60 year old man
- Palpitations
- AF

AF



Reality at the bedside

- No personalised tools for predicting risk of AF
- New drugs, but which one?
- No notes from GP/patient/hospital

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Cascade of waste

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Science: What causes AF? What are the risk factors?
Evidence: New drugs, but which one?
Care: No notes from GP/patient/hospital

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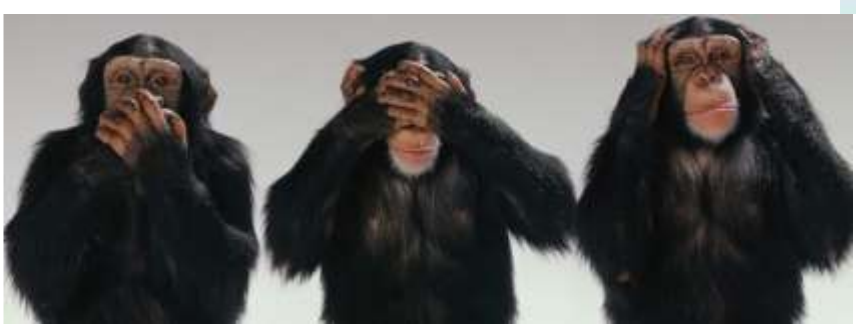
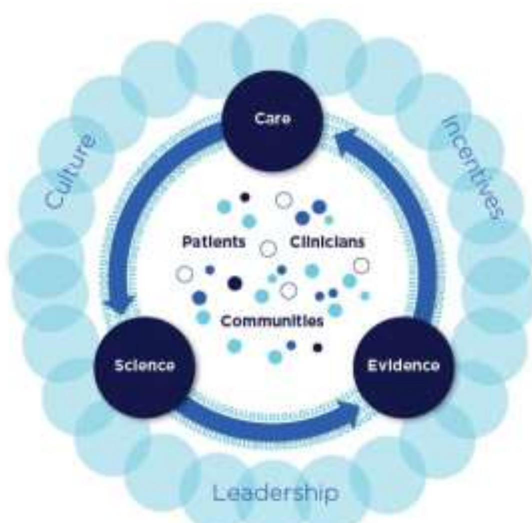
Neglecting any of these three factors can be detrimental to individuals and patients



PEOPLE WHO LIKE TO DRAW CYCLES

Continuously learning healthcare system



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The scope of LHS

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Learning Health Systems

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Not this

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EHR

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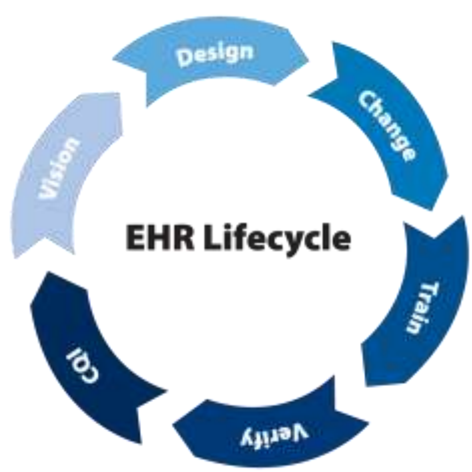

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IT and learning health systems

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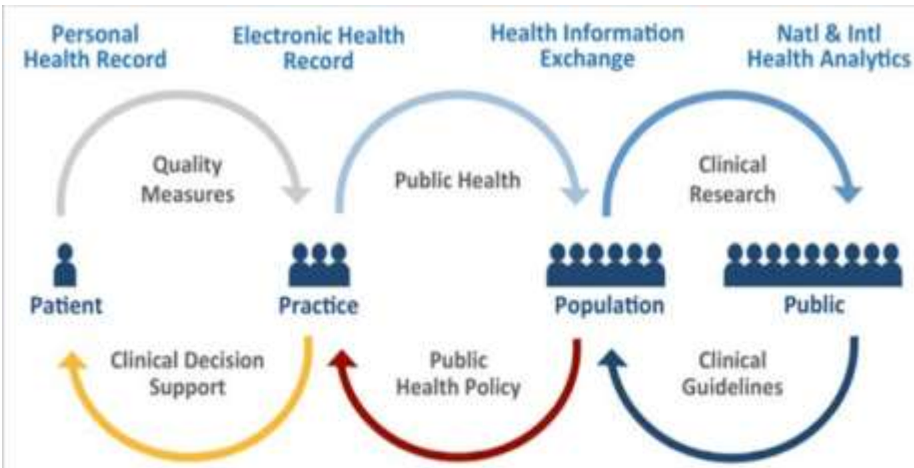

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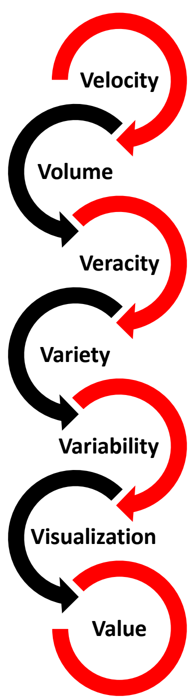
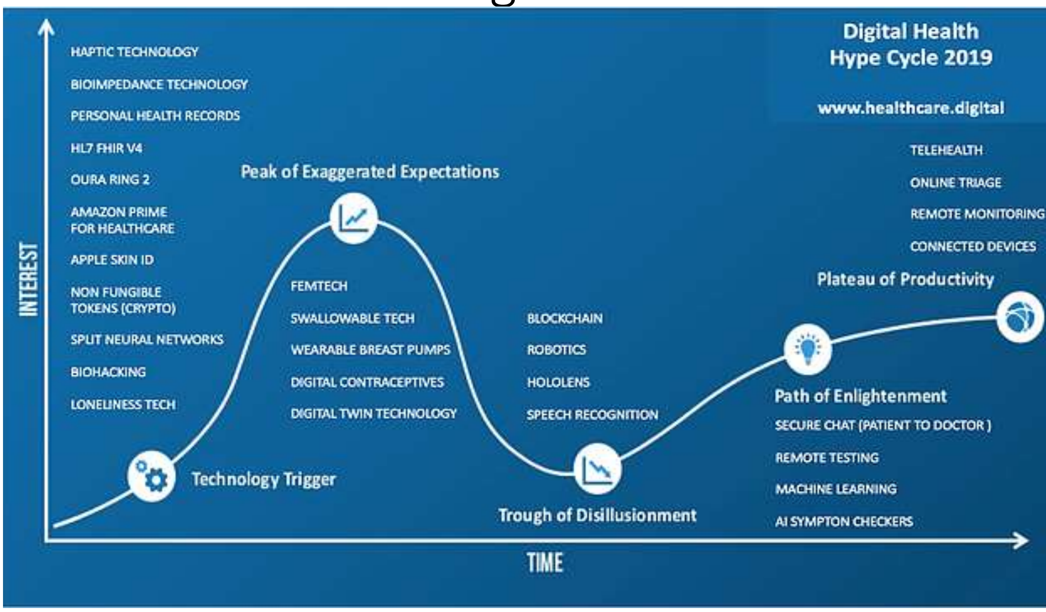


Big Data is Out



Patient-centred healthcare

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The gap between promise and reality

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Conclusions

This review identified some benefits in the quality of care but did not provide evidence that the implementation of eHealth interventions had a measurable impact on cost-effectiveness in hospital settings. However, further evidence is needed to infer the impact of standards adoption or interoperability in cost benefits of health care; this in turn requires further research.

PubMed Health

Conclusions: PROMs data act as 'tin openers' rather than 'dials'. Providers need more support and guidance on how to collect their own internal data, how to rule out alternative explanations for their outlier status and how to explore the possible causes of their outlier status. There is also tension between PROMs as a QI strategy versus their use in the care of individual patients; PROMs that clinicians find useful in assessing patients, such as individualised measures, are not useful as indicators of service quality.

Conclusion: For every hour physicians provide direct clinical face time to patients, nearly 2 additional hours is spent on EHR and desk work within the clinic day. Outside office hours, physicians spend another 1 to 2 hours of personal time each night doing additional computer and other clerical work.

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CLEANING THE MESS

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Science

- Analysis of risk factors
- Improve disease definition
- Risk prediction models
- Inform future discovery science and trials
- Understanding of disease mechanism and drug targets

Evidence

- Automation/machine learning built into EHR for evidence/guidelines
- Real world EHR trials
- Comparative effectiveness research
- Surveillance
- Personalised recommendation

Care

- Prospective not retrospective
- Decision support
- Real-time linkage
- Interoperability
- Include patient experience, wearable and –omic data
- Patient can see and use their own data


A promise to learn
– a commitment to act

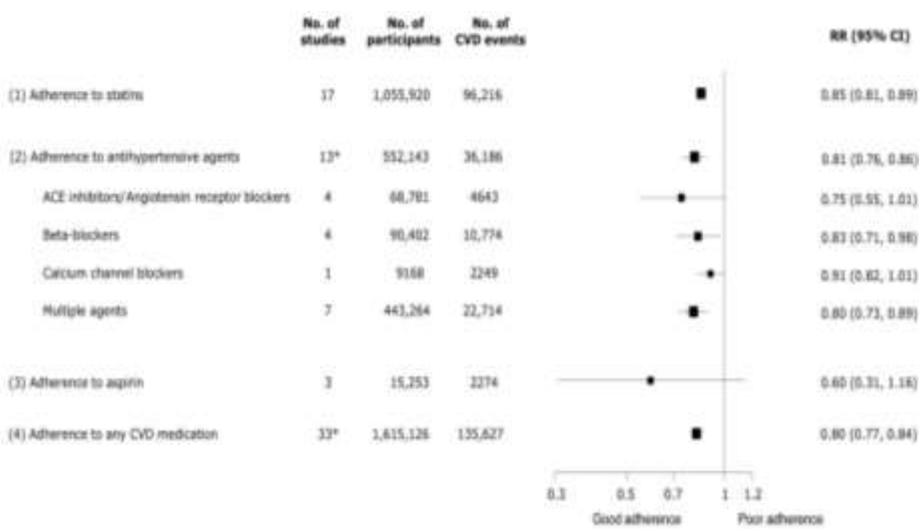
Improving the Safety of Patients in England

National Advisory Group on the Safety of Patients in England

Reviews emphasising IT and research

- Francis 2013
- Keogh 2013
- Wachter 2016
- Caldicott 2017
- Topol 2018
- <u>We don't need more reviews and reports</u>

Adherence and CVD events



Chowdhury et al. EHJ. 2013.

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Adherence and deaths

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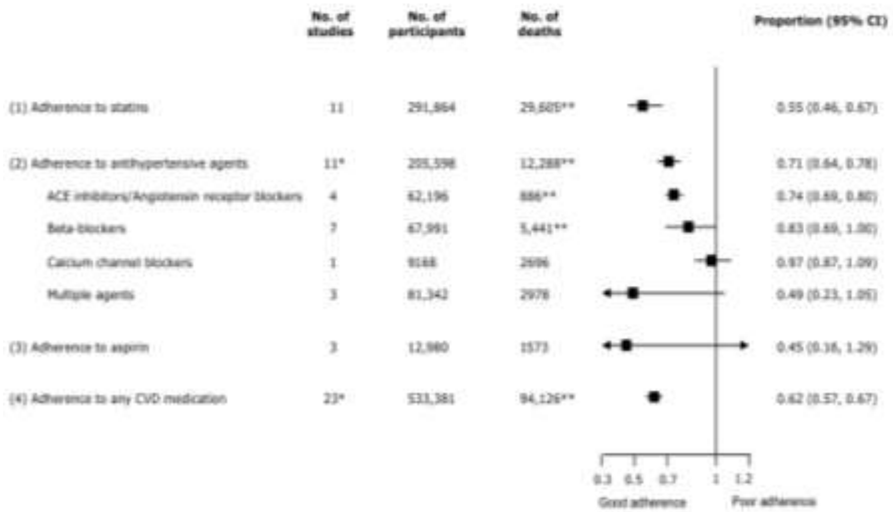

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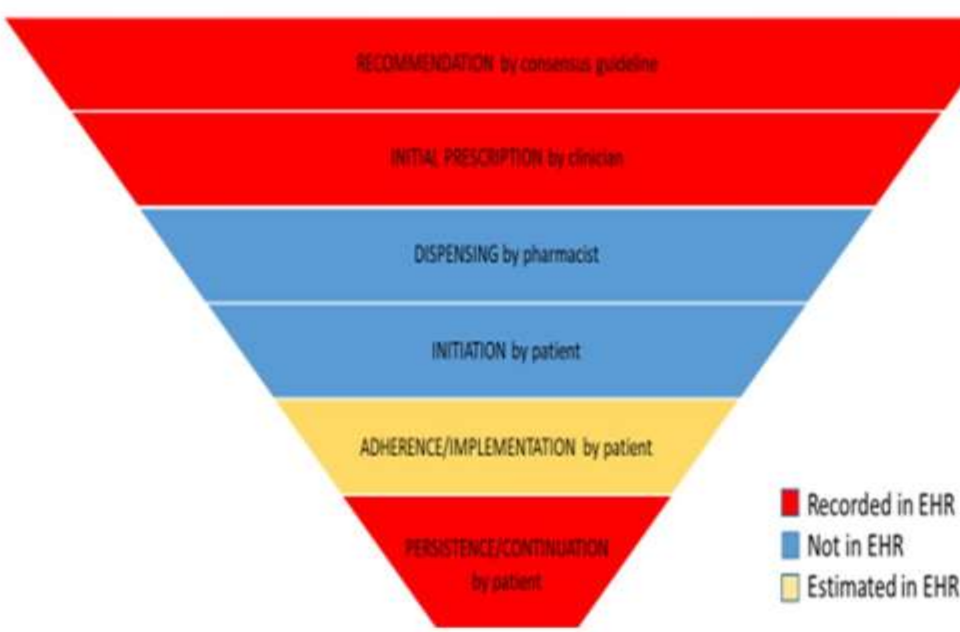

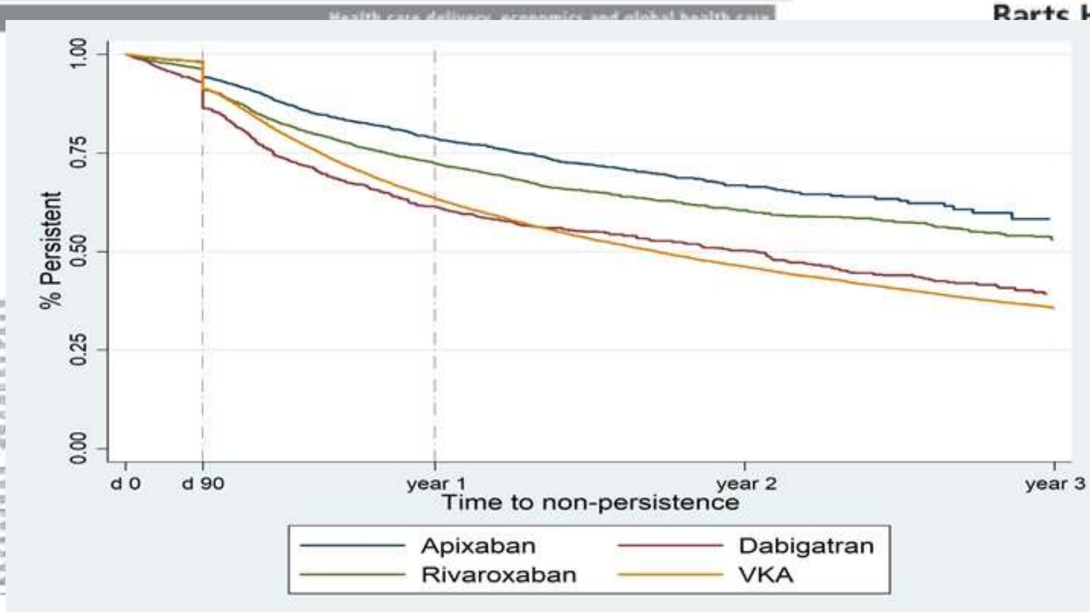

Value (1)

	2008	2012	2016
HF	• Systolic • Diastolic	• HFrEF (LVEF<35%) • HFpEF (LVEF>50%) structural heart disease, diastolic dysfunction	• HFrEF (LVEF<40%) • HFmrEF (LVEF 40-49%) • HFpEF (LVEF≥50%) BNP, structural heart disease, diastolic dysfunction
	2006	**2010**	**2016**
AF	• First detected • Paroxysmal (self-terminating) • Persistent(non self-terminating) • Permanent	• Paroxysmal (usually≤48 hrs) • Persistent (>7 days or requires CV) • Long-standing Persistent (>1 yr) • Permanent	• AF secondary to structural heart disease • Focal AF • Polygenic AF • Post-operative AF • AF in patients with mitral stenosis or prosthetic heart valves • AF in athletes • Monogenic AF

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Value (2)

- Human and machine readable
- Validated
- Stakeholder acceptability

- Multiple phenotypes (e.g. 8 for AF)
- Multiple data types
  - Hospital and primary care EHR
  - Trial data
  - Registry data
- Multiple countries

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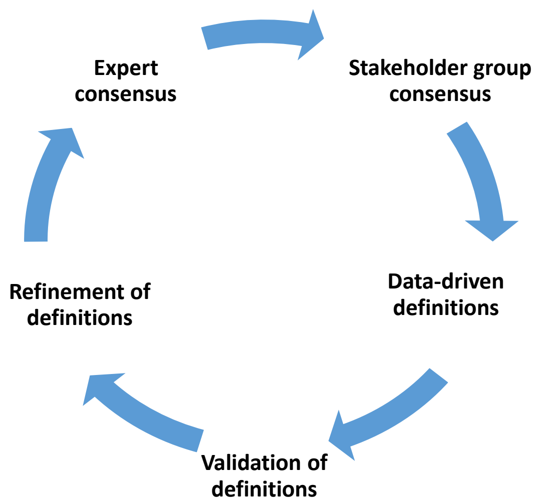
Value (3)

Value (4)

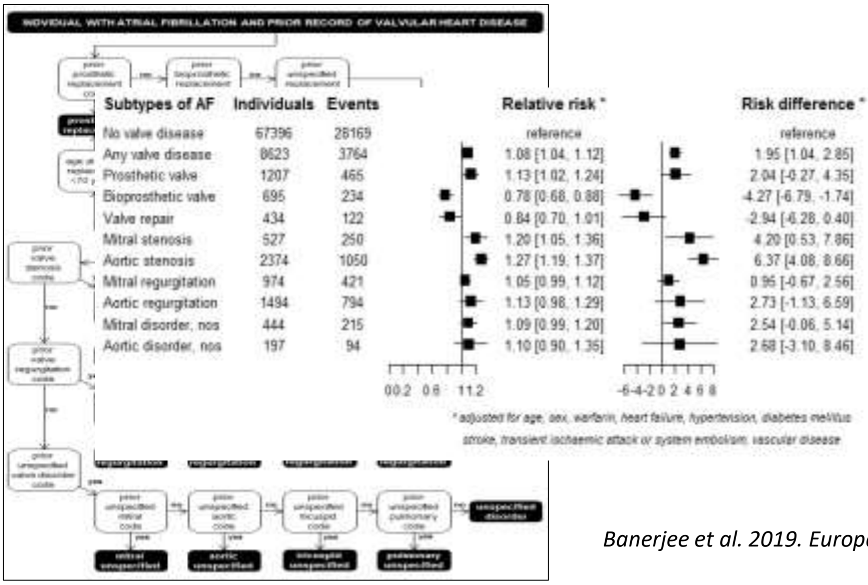
WP2: Disease understanding and outcomes definition



Value (5)

AF type	EHR phenotype description	ICD 10	Read	OPCS 4	BNF	Refs.
AF secondary to structural heart disease	▪ LV systolic/diastolic dysfunction, and/or heart failure ▪ Long-standing hypertension with LV hypertrophy ▪ Congenital heart malformations ▪ Cardiomyopathies ▪ Valvular heart diseases ▪ Other structural heart disease	✓	✓	✓	✓	1-4
Focal AF	▪ Paroxysmal AF ▪ Symptomatic AF ▪ Atrial ectopy and/ or atrial tachycardia	✓	✓			1
Polygenic AF	▪ Inferred: very early onset AF not elsewhere classified					1,5
Post-operative AF	▪ Open / closed cardiac surgery ▪ Other/ any surgery			✓		1,6,7
AF with mitral stenosis/ prosthetic valves	▪ Mitral stenosis ▪ Prosthetic heart valves	✓	✓	✓		1,8
AF in athletes	▪ Professional, or high level sports participation ▪ Inferred: Other sports occupations e.g. sports coaches could infer former athletes		✓			1
Monogenic AF	▪ Long-QT, Brugada, Wolff-Parkinson-White syndrome	✓	✓			1,4
AF secondary to respiratory disease *	▪ COPD ▪ Sleep apnoea ▪ Pulmonary hypertension	✓	✓			1,9

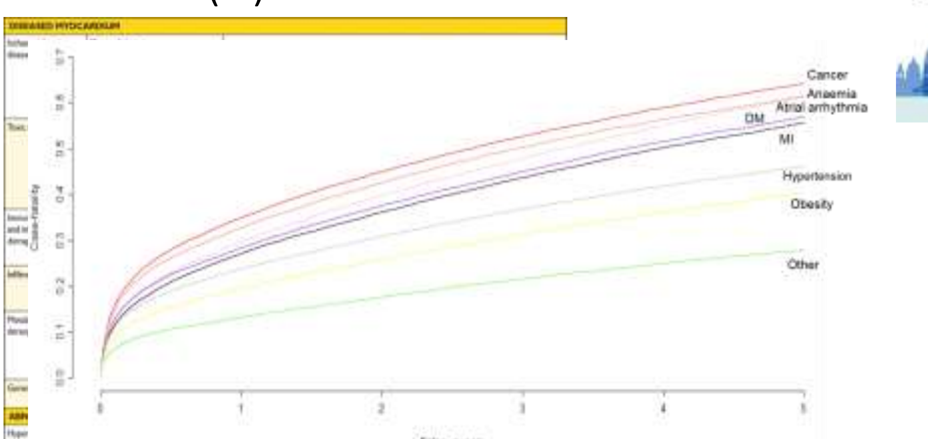
Value (6)



Subtypes of AF	Individuals	Events	Relative risk *	Risk difference *
No valve disease	67396	28169	reference	reference
Any valve disease	8623	3764	1.08 [1.04, 1.12]	1.95 [1.04, 2.85]
Prosthetic valve	1207	465	1.13 [1.02, 1.24]	2.04 [-0.27, 4.35]
Bioprosthetic valve	695	234	0.78 [0.68, 0.88]	-4.27 [-6.79, -1.74]
Valve repair	434	122	0.84 [0.70, 1.01]	-2.94 [-6.28, 0.40]
Mitral stenosis	527	250	1.20 [1.05, 1.36]	4.20 [0.53, 7.86]
Aortic stenosis	2374	1050	1.27 [1.19, 1.37]	6.37 [4.08, 8.66]
Mitral regurgitation	974	421	1.05 [0.99, 1.12]	0.95 [-0.67, 2.56]
Aortic regurgitation	1494	794	1.13 [0.98, 1.29]	2.73 [-1.13, 6.59]
Mitral disorder, nos	444	215	1.09 [0.99, 1.20]	2.54 [-0.06, 5.14]
Aortic disorder, nos	197	94	1.10 [0.90, 1.35]	2.68 [-3.10, 8.46]

Banerjee et al. 2019. Europace

Value (7)



Main category	Abnormal loading	Diseased myoc	Arrhythmias	Diseased myocardium			Abnormal loading	Other
Leading risk category	Hypertension	Obesity	Atrial arrhythmia	Cancer	MI	Diabetes	Severe anaemia	Other
N	82921	51088	29399	28184	36994	25841	24352	18736
Age mean, SD	74.7, 13.1	71.1, 13.4	79.6, 10	79.5, 10.5	76, 11.3	75.1, 11.2	77.6, 13.1	64.4, 16.9
Cumulative death rate at 5th year	46.2 (45.8,46.6)	40.6 (40.1,41.1)	61.3 (60.7,62)	64.3 (63.6,64.9)	55.7 (55,56.4)	57 (56.3,57.7)	61.5 (60.8,62.2)	27.9 (27.3,28.8)

Green: other, yellow: obesity , grey: hypertension, black: MI (myocardial infarction), purple: DM (diabetes), pink: atrial arrhythmia, salmon anaemia , red: cancer

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Value (8)

1. Interoperability
   - Across study designs
   - Across clinical settings
   - Across universities and hospitals
   - Across countries
2. Agreement of coding and definitions
3. Improved quality and use of routine clinical data
4. Potential EHR trials

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VITAL DIRECTIONS FROM THE NATIONAL ACADEMY OF MEDICINE

Health Information Technology Interoperability and Use for Better Care and Evidence

-Commit to end-to-end interoperability extending from devices to EHR systems.

-Aggressively address cyber security vulnerability.

-Develop a data strategy that supports a learning health system.

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Science

- HDR-UK

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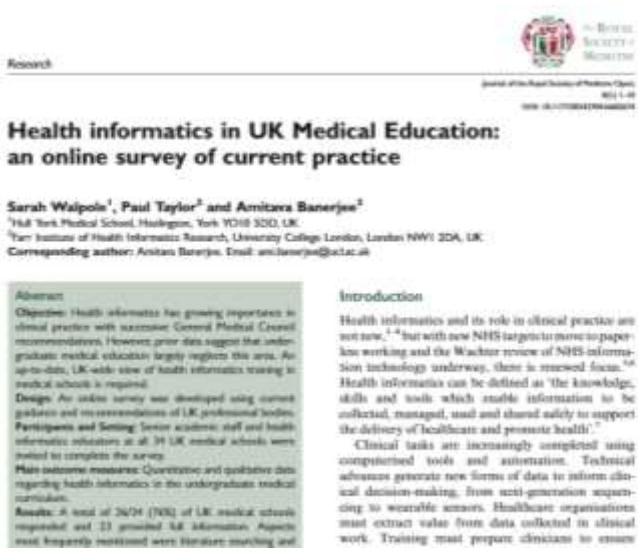
Undergraduate medical training in HI


Research

Health informatics in UK Medical Education: an online survey of current practice

Sarah Walpole[1], Paul Taylor[2] and Amitava Banerjee[2]
[1]Hull York Medical School, Heslington, York YO10 5DD, UK
[2]Farr Institute of Health Informatics Research, University College London, London NW1 2DA, UK
Corresponding author: Amitava Banerjee. Email: ami.banerjee@ucl.ac.uk

Abstract
Objective: Health informatics has growing importance in clinical practice with successive General Medical Council recommendations. However prior data suggest that undergraduate medical education largely neglects this area. An up-to-date, UK-wide view of health informatics training in medical schools is required.
Design: An online survey was developed using current guidance and recommendations of UK professional bodies.
Participants and Setting: Senior academic staff and health informatics educators at all 34 UK medical schools were invited to complete the survey.
Main outcome measures: Quantitative and qualitative data regarding health informatics in the undergraduate medical curriculum.
Results: A total of 26/34 (76%) of UK medical schools responded and 23 provided full information. Aspects most frequently mentioned were literature searching and

Introduction

Health informatics and its role in clinical practice are not new,[1-4] but with new NHS targets to move to paperless working and the Wachter review of NHS information technology underway, there is renewed focus.[5,6] Health informatics can be defined as 'the knowledge, skills and tools which enable information to be collected, managed, used and shared safely to support the delivery of healthcare and promote health'.[7]

Clinical tasks are increasingly completed using computerised tools and automation. Technical advances generate new forms of data to inform clinical decision-making, from next-generation sequencing to wearable sensors. Healthcare organisations must extract value from data collected in clinical work. Training must prepare clinicians to ensure

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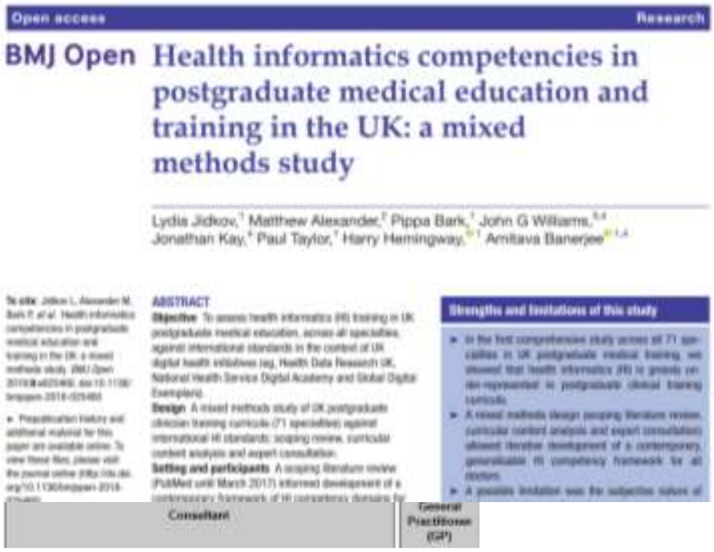
Postgraduate training in HI


Open access | Research

BMJ Open **Health informatics competencies in postgraduate medical education and training in the UK: a mixed methods study**

Lydia Jidkov,[1] Matthew Alexander,[2] Pippa Bark,[1] John G Williams,[3,4] Jonathan Kay,[4] Paul Taylor,[1] Harry Hemingway,[1] Amitava Banerjee[1,4]

ABSTRACT

Strengths and limitations of this study

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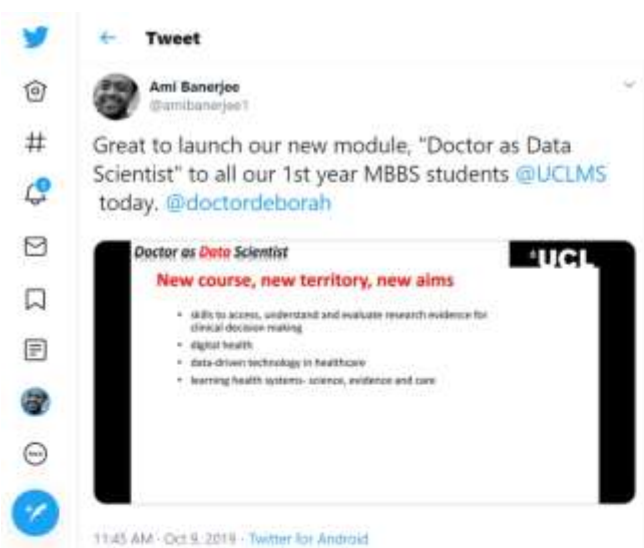
Undergraduate training in HI



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Postgraduate training in HI

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British Cardiovascular Society
"Promoting excellence in cardiovascular care"

Digital Cardiology

A British Cardiovascular Society National Symposium

British Cardiovascular Society, London, 1st November 2019

08:30 – 09:00	Registration	
09:00 – 09:10	Welcome and Introduction to digital cardiology	Dr Amitava Banerjee Dr Shouvik Haldar
Session 1	**Artificial Intelligence in Cardiology**	
09:10 – 09:30	Use of artificial intelligence in cardiology	Professor Steffen Petersen
09:30 – 09:50	Systematic review of clustering and prediction in CVD	Dr Amitava Banerjee
09:50 – 10:10	Machine learning in cardiovascular risk prediction-ready for prime time?	Professor Mihaela van der Schaar
10:10 – 10:40	Panel discussion – Open to Floor Artificial Intelligence – Hope or hype for cardiology?	Chair: Professor Steffen Petersen

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Evidence

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- Digital Academy
- Faculty of Clinical Informatics (FCI)
- Federation of Informatics Professionals (Fed-IP)

NHS England

Search news

News

Top universities will host new Academy to train digital healthcare leaders of the future

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Care

- Global Digital Exemplar programme

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All commentary?

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All commentary?

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SPECIAL ARTICLE

Big Data for cardiology: novel discovery?

Viktor Mayer-Schönberger

REVIEWS

Big data analytics to improve cardiovascular care: promise and challenges

Are We Up to Speed?

From Big Data to Rich Insights in CV Imaging for a Hyperconnected World

Jagat Narula, MD, PhD

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All commentary?

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SPECIAL ARTICLE

Big Data for cardiology: novel discovery?

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REVIEWS

Preventive Cardiology

Data-driven healthcare: from patterns to actions

M Greenhalgh and H Bann

Viewpoints

Harnessing the Heart of Big Data

Sarah B. Scruggs, Karol Watson, Andrew I. Su, Henning Hermjakob, John R. Yates III, Merry L. Lindsey, Peipei Ping

re We Up to Speed?

om Big Data to Rich Insights in CV Imaging for a Hyperconnected World

gat Narula, MD, PhD

Outstanding problems

- Is {…} making healthcare more efficient?
- Is {…} making healthcare more effective?
- Is {…} reducing inequalities?
- Is {…} causing harm?
- Is {…} aligning research and care?
- Is {…} dealing with ethical and regulatory concerns?

Summary

- Define the mess
- Draw cycles
- Clean the mess

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Patient-centred vs Researcher/Data/Tech-centred

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SCIENCE TRANSLATIONAL MEDICINE | EDITORIAL

POLICY

The study is open: Participants are now recruiting investigators

Recent events inspire optimism that a new age is dawning, one in which lay people have an active role in advancing biomedical research and health care delivery. Two ongoing experiments will deeply involve the public in these endeavors: the U.S. Precision Medicine Initiative (PMI) and the National Patient-Centered Clinical Research Network (PCORnet). PCORnet has already launched 20 patient-powered research networks designed to be led and animated by people who have an affinity with one another because of either shared disease, geography, experience, or identity (1). When U.S. President Barack Obama announced the PMI, he stated emphatically that people would be, not patients or even participants, but rather, partners in clinical research (2, 3). In the hours and days that followed, Francis Collins, director of the U.S. National Institutes of Health (NIH), reiterated this view, using words such as "participant" and "partner" when referring to people involved in clinical research (1). As a veteran citizen scientist and patient advocate (4), I was moved to tears to hear such proclamations from people other than my passionate fellow advocates. However, PCORnet's efforts and PMI's endeavor to enroll a million people—called All of US—will spur the advancements we seek only if we, the people, take advantage of these unprecedented opportunities and act with boldness to overcome myriad misaligned incentives, business interests, and general inertia against change.

BUILDING THE WE: TRUE PARTICIPATION

Thousands of individuals affected by common and rare ... the investigators and not by all stakeholders. Participants want not only to be invited to the table but also to design and host the meal with other stakeholders. There is a great deal of "us and them" language in biomedical research. Investigators point to "those patients," and activists complain about "those investigators." Clinicians are often left out of the process completely. When these roles are considered dichotomous and separate instead of part of a continuum, it is difficult to create authentic partnerships.

Participants have a place throughout the research continuum, including the proposal and prioritization of research questions, study design, engagement of study participants and their recruitment and retention, conduct of research and data analysis, and implementation and dissemination of results and, often, individuals' own data. However, if we intend to engage a large and diverse array of people in clinical research, participation has to be made as frictionless as possible by creating mechanisms in communities where people live, work, and play, with community representatives leading the way. In addition, the research conducted must have relevance to the engaged parties by addressing questions that arise from communities of participants. If a study is built on the needs of individuals, families, and communities, then the results of research must be transparent and tangible—traits that run counter to the current culture. Researchers often do not return even the published results to the participants, let alone a lay summary or other accessible communication. If an effective intervention results from a clinical study, the process can take more than 10 years for the new intervention to be integrated into clinical practice (5). The new U.S. national efforts, particularly

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People not data

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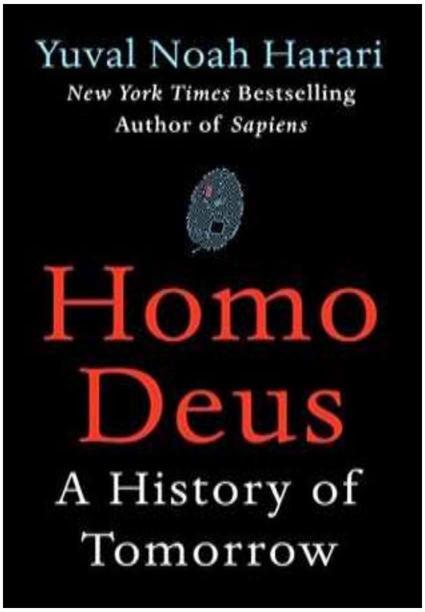
"He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all."

William Osler

"It's important to remember that behind every data point is a daughter, a mother, a sister – a person with hopes and dreams."

Melinda Gates



- “In the early twenty-first century the train of progress is again pulling out of the station – and this will probably be the last train ever to leave the station called Homo sapiens. Those who miss this train will never get a second chance. In order to get a seat on it you need to understand twenty-first-century technology, and in particular the powers of biotechnology and computer algorithms.”